



**CABINET FOR HEALTH AND FAMILY SERVICES
DEPARTMENT FOR PUBLIC HEALTH**

Matthew G. Bevin
Governor

275 East Main Street, 5W-A
Frankfort, KY 40621
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Adam M. Meier
Secretary

May 6, 2019

Matthew G. Bevin
Governor
700 Capitol Avenue, Suite 100
Frankfort, KY 40601

Dear Governor Bevin,

Pursuant to KRS 211.597 (4), enclosed is the 2018 Pediatric Cancer Research Trust Fund Annual Report for your review.

This document is a collaborative effort between the Kentucky Department for Public Health and the Pediatric Cancer Research Trust Fund Board. This report includes a summary of data compiled from the Kentucky Cancer Registry, as related to incidence, burden and survival of pediatric cancers in Kentucky. It also includes the objectives that the Kentucky Cancer Consortium has included in the Kentucky Cancer Action Plan that specifically address childhood cancer survivors.

If you have questions about the report, please contact Connie Gayle White, MD, Senior Deputy Commissioner of the Department for Public Health at 564-3970.

Sincerely,

A handwritten signature in dark ink, appearing to read "Adam M. Meier", written in a cursive style.

Adam M. Meier
Secretary
Cabinet for Health and Family Services





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Adam M. Meier
Secretary

May 6, 2019

Becky Harilson, Director
David Floyd, Director
Legislative Research Commission
Room 300, Capitol
Frankfort, Kentucky 40601

Dear Ms. Harilson and Mr. Floyd:

Pursuant to KRS 211.597(4), enclosed is the 2018 Pediatric Cancer Research Trust Fund Annual Report for your review.

This document is a collaborative effort between the Kentucky Department for Public Health and the Pediatric Cancer Research Trust Fund Board. This report includes a summary of data compiled from the Kentucky Cancer Registry, as related to incidence, burden and survival of pediatric cancers in Kentucky. It also includes the objectives that the Kentucky Cancer Consortium has included in the Kentucky Cancer Action plan that specifically address childhood cancer survivors.

If you have questions about the report, please contact Connie Gayle White, MD, Senior Deputy Commissioner of the Department for Public Health at 564-3970.

Sincerely,

A handwritten signature in blue ink, appearing to read "Adam M. Meier".

Adam M. Meier
Secretary

cc: Jeffrey D. Howard, Jr., MD, Commissioner, Kentucky Department for Public Health
Connie Gayle White, MD, Senior Deputy Commissioner, Department for Public Health

Enclosure



Annual Report FY 2018

Prepared By:

**The Kentucky Department for Public Health
Chronic Disease Prevention Branch in collaboration with
The Kentucky Pediatric Cancer Research Trust Fund Board**

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Annual Report on the Kentucky Pediatric Cancer Research Trust Fund

This report was prepared by the
Division of Prevention and Quality Improvement
Kentucky Department for Public Health
Cabinet for Health and Family Services
And
The Kentucky Pediatric Cancer Research Trust Fund Board

Date of Report: February 4, 2018

Kentucky Pediatric Cancer Research Trust Fund Board Members

Jamie Ennis Bloyd, MPA, Citizen-At-Large, Board President
Adam Meier, Secretary, Cabinet for Health and Family Services
Bradley Nunn, BS, Representing the Kentucky Chapter of the Leukemia and Lymphoma Society
Jeffrey Howard, MD, Commissioner, Department for Public Health
Ashok Raj, MD, Representing Norton Children's Hospital
James Sharp, Mid-South American Cancer Society Cancer Action Network, Inc.
Heather Shaw, Citizen-At-Large
John D'Orazio, MD, Chief, Division of Pediatric Hematology/Oncology, Kentucky Children's Hospital
Heather Hood Wise, DMD, Citizen-At-Large

Department for Public Health Contributing Staff

Devon McFadden, Division Director, Division of Prevention and Quality Improvement
Sue Thomas-Cox, RN, Branch Manager, Chronic Disease Prevention Branch
Janet C. Luttrell, Kentucky Pediatric Cancer Research Trust Fund Program Manager, Chronic Disease Prevention Branch

Report Overview

This report is prepared pursuant to KRS 211.597 (Appendix A), which states that “a report be provided to the Governor and the Legislative Research Commission (LRC) detailing the plan developed for the expenditure of funds for the current and next fiscal year, a summary of the use and impact of prior year funds, a summary of the activities of the board during the prior fiscal year, and any recommendations for future initiatives or action regarding pediatric cancer research funding.”

History

In 2015, legislation was enacted creating the Kentucky Pediatric Cancer Research Trust Fund (KPCRTF) under KRS 211.595 (Appendix A). The purpose of the fund is to support pediatric cancer research and treatment in Kentucky. The KPCRTF board was created under KRS 211.596 (Appendix A) detailing the makeup of the board membership, terms of membership, and meeting details. The board is attached to the Cabinet for Health and Family Services (CHFS). In 2018, funding in the budget was allocated by the legislature to the KPCRTF in the amount of \$5,000,000 for FY 19 through FY 20.

KRS 211.597 authorizes the KPCRTF board to promulgate administrative regulations necessary to carry out the provisions of KRS 211.595 to 211.597, including the establishment of a competitive grant program to provide funding to organizations offering programs or services in the areas of pediatric cancer research and treatment. Accordingly, in March 2017, the Kentucky Department for Public Health (KDPH) filed the KPCRTF regulation and on June 21, 2017 the administrative regulation, which established the requirements of the KPCRTF Program, went into effect.

Plan for Expenditure of Funds

Summary of Existing Research, Awareness, Treatment and Funding Programs

Specific language in the budget bill appropriated \$2.5 million each to the University of Kentucky and the University of Louisville, Kentucky’s two children’s oncology group hospitals, for pediatric cancer research aimed at improving outcomes for Kentucky children diagnosed with cancer for the biennium July 1, 2018 through June 30, 2020. This is a new appropriation; therefore, there is no summary of pre-existing research, awareness, treatment, and funding programs specific to this line item.

Below is a summary of each project selected for funding. This panel was comprised of the following leaders in the field of pediatric cancer research and treatment: panel chair, John Perentesis, MD, Cincinnati Children’s Hospital Medical Center; Stewart Goldman, MD, Lurie Children’s Hospital, Chicago; and Douglas Graham, MD, Children’s Hospital of Atlanta.

The University of Louisville shall:

Primary Objective #1 – Pilot Study Eflornithine/DFMO – FY19 - \$14,000 and FY20 - \$14,000

- 1) To evaluate the maximum tolerated dose (MTD) of difluoromethylornithine (DFMO) as a single agent in patients with relapsed or refractory Sonic Hedgehog Molecular Subgroup (SHH) activated, Group 3 or other MYC oncogene (MYC) amplified medulloblastoma.

Secondary Objectives

- a. To verify peak serum concentrations (C_{max}), time at max drug concentration (T_{max}), and Area under the Curve (AUC) in medulloblastoma patients after administration of DFMO. Serum will be collected at hours 0, 0.5, 1, 3 and 6 hours of first dose administration.
- b. To document cerebrospinal fluid (CSF) and urine concentrations after DFMO administration. CSF will be collected at hour 24 following first dose administration. Urine polyamine measurements to be obtained at baseline and weekly for 3 total measurements after starting DFMO.
- c. To determine overall response rate (complete responses + partial responses + stable disease) in relapsed/refractory SHH activated, Group 3 or other MYC-amplified medulloblastoma after receiving DFMO for up to 13 cycles. Complete response (CR) is defined by the disappearance of all lesions whereas partial response (PR) is defined by a greater than 30% decrease in tumor size.

Primary Objective #2 - Anti-CD33-CD123 Compound CAR-T Cells – Pediatric Acute Myeloid Leukemia – FY19 - \$625,000 and FY20 - \$625,000

- 1) Develop a compound chimeric antigen receptor-expressing T cells (CAR-T) approach to combat childhood Acute Myeloid Leukemia (AML).

Secondary Objectives

- a. Improve the safety profile of anti-CD33/CD123 compound CAR-T cells by incorporating a safety switch.
- b. Optimize the manufacturing processes to produce clinical-grade anti-CD33/CD123 compound CAR-T cells.
- c. Characterize quantitatively the cytotoxic activity of anti-CD33/CD123 compound CAR-T cells directed against human AML cell lines and primary isolates.
- d. Generate data on the viability, purity, stability, activity, and safety of anti-CD33/CD123 compound CAR-T cells produced in compliance with current Good Manufacturing Practice (cGMP) requirements.

Primary Objective #3 – Anti-GD2 CAR-T Cells with Intrinsic PD-1 Checkpoint Blockade for the Treatment of Pediatric Neuroblastoma and Brain Tumors – FY19 - \$625,000 and FY20 - \$625,000

- 1) Develop a CAR-T cell approach to combat childhood pediatric neuroblastoma and brain tumors.

Secondary Objectives

- a. Improve the cytotoxicity profile of anti-GD2 disialoganglioside (GD2) CAR-T cells by incorporating intrinsic programmed cell death protein 1 (PD-1) blockade.
- b. Optimize the manufacturing processes to produce clinical-grade anti-GD2 CAR-T cells.
- c. Characterize quantitatively the cytotoxic activity of anti-GD2 CAR-T cells directed against human neuroblastoma and brain tumor cell lines and primary isolates.
- d. Generate pre-clinical data on the viability, purity, stability, activity, and safety of anti-GD2 CAR-T cells produced in compliance with cGMP requirements.

The University of Kentucky shall:

Primary Objective #1 – Provide Support for Siblings of Pediatric Cancer – FY19 - \$8,000 and FY20 - \$8,000

- 1) Estimate the incidence of psychological stress and the potential impact on siblings of pediatric cancer patients using a parent survey.
- 2) Assess the potential utility of strategies to raise awareness for identification and early intervention for at-risk siblings.

Secondary Objectives

- a. Identify 50 oncology patients with siblings who have been treated at Kentucky Children's Hospital and were diagnosed between 2014-2016.
- b. Contact parents and ask for their willingness to participate.
- c. Consenting parents will then complete a questionnaire focusing on the potential impact and stress experienced by the sibling(s) of the cancer patient. Areas of interest will include sleep disturbances, school absences and performance, new medical complaints, medication usage, and parents' perception of overall happiness and stress with the sibling(s).
- d. Parents will also be asked whether they pursued any interventions for problems that arose in the sibling(s), and how they would feel about the development of strategies for earlier detection and intervention.
- e. Identify 20 patients with siblings who were diagnosed with cancer in 2017 and are being treated at Kentucky Children's Hospital.
- f. Discuss with the parents the potential psychological risks for siblings of pediatric cancer patients, and for consenting families.

- g. Distribute customized information packets to the sibling's school guidance counselor and primary care provider's office. The packets will contain a summary of the treatment plan for the cancer patient, as well as general information regarding the stress-related problems that may be encountered in siblings.
- h. Specific details on common warning signs will be included, as will details about possible intervention strategies such as relaxation exercises, as well as counseling.
- i. When applicable, information about possible counseling options will be provided. For example, siblings of pediatric cancer patients may be eligible for free counseling services provided through local hospices, even if the cancer patient is not enrolled in the hospice.
- j. It is hypothesized that raising awareness in the parents and "first responders" (e.g., school personnel and primary care providers) may help more rapidly identify patients who could benefit from interventions such as counseling.
- k. To assess the utility whether these interventions do indeed increase awareness, questionnaires will be administered to the school officials and primary care providers both before and after the information packages are sent.
- l. In the second survey we will ask about the status of the sibling and whether problems have been recognized.
- m. This information will be pooled with data from the parental surveys above to help compile information on potential features that may help us identify siblings at highest risk who may be suitable for earlier interventions.

Primary Objective #2 – Circulating Tumor DNA as a Prognostic Indicator of Minimal Residual Disease and Central Nervous System Relapse in Acute Lymphoblastic Leukemia – FY19 - \$220,000 and FY20 - \$220,000

- 1) Develop a new assay that quantifies cell-free circulating tumor DNA (ctDNA) to sensitively and non-invasively monitor Acute Lymphoblastic Leukemia (ALL) response to conventional chemotherapy and potentially allow for earlier detection of relapse.

Secondary Objectives

- a. Create a biobank of primary leukemia samples from Kentucky pediatric ALL patients.
- b. Determine the extent to which ctDNA in blood and cerebrospinal fluid (CSF) of ALL patients predicts or correlates with clinical diagnosis of minimal residual disease and relapse.
- c. Develop a universal droplet digital polymerase chain reaction (ddPCR) assay to detect ctDNA in ALL patients.

Primary Objective #3 – Chemotherapy Induced Cognition Impairment – Mechanisms and Prevention – FY19 - \$230,000 and FY20 - \$230,000

- 1) Develop extracellular vesicles (EVs) as an early and non-invasive biomarker of cancer chemotherapy induced cognition impairment (CICI) in children and provide a rapid path to enter clinical trials for therapeutic intervention using the prototype drug MESNA, an FDA approved drug that inhibits reactive oxygen species (ROS) without affecting the efficacy of cancer therapeutics.

Secondary Objectives

- a. Evaluate the EVs for their effect on human immune cells to determine the mechanistic links between circulating EVs and therapy induced immune activation.
- b. Determine the effect of MESNA on immune activation and neuronal injury to investigate the immune mediated mechanism of CICI.
- c. Characterize EVs isolated from children before and after completion of induction and consolidation chemotherapy to gain insights into mechanisms of brain injury after systemic and intrathecal chemotherapy.

Primary Objective #4 – Factors Associated with High Incidence of Pediatric Brain and Central Nervous System Tumors in Kentucky – FY19 - \$260,000 and FY20 - \$262,371

- 2) Develop a population-specific study to identify factors associated with the high incidence of Pediatric Brain and Central Nervous System Tumors (PBCNST) in Kentucky, leveraging the infrastructure provided by the Kentucky Cancer Registry (KCR), its Virtual Tissue Repository and the National Institutes of Health (NIH) Kids First Data Resource Center (DRC).

Secondary Objectives

- a. Identify potential environmental exposures associated with Kentucky's high rate of brain and central nervous system (CNS) tumors.
- b. Assess whether Kentucky-specific mutations and mutational signatures exist that may be related to PBCNST, and to determine whether known genetic risk factors for PBCNST are present among Kentucky children.
- c. Enhance mitomycin C (MCC) informatics infrastructures for sustained and ongoing integration of our datasets and research with the consortia-based research efforts of the Children's Hospital of Philadelphia (CHOP), Children's Brain Tumor Tissue Consortium (CBTTC), Pacific Pediatric Neuro-Oncology Consortium (PNOC), and the Kids First Data Resource Center (DRC).

Primary Objective #5 – Investigational new Drug Enabling Studies of Mithramycin Derivatives for the Treatment of Ewing Sarcoma – FY19 - \$540,000 and FY20 - \$537,629

3) Advance a compound toward clinical development.

Secondary Objectives

- a. Demonstrate the increased therapeutic window and safety of the mithramycin SA (MTMSA) analogue.
- b. Obtain large quantities of MTMSA via industrial scale bacterial fermentation conducted by a contract research organization (CRO).
- c. Conduct defined pharmacology, toxicity and safety studies with MTMSA-A10 that are required for the submission of an investigational new drug application to the FDA.

Needs Assessment

The Kentucky Cancer Registry (KCR) has developed a population-based childhood cancer incidence report for the Commonwealth of Kentucky. KCR collects uniform, high quality data on approximately 215 new primary cases of childhood cancer occurring in Kentucky residents each year. This report provides detailed information about childhood cancer in Kentucky for the most recent ten-year period of complete, population-based data collected and validated by KCR. The report also provides information about age-adjusted childhood cancer incidence rates. Childhood Cancer in Kentucky 2007-2016 is included in this document as Appendix B. This data demonstrates the urgent need for the appropriated funds to be utilized for state research and improving outcomes for children diagnosed with cancer in Kentucky. The data also provides insight into which types of childhood cancer diagnoses are being observed beyond what should statistically be expected.

Prioritized List of Programs and Research Projects to be Addressed

Language included in the KPCRTF Request for Applications reflects the priorities established by the board in selection of programs and research projects to be funded. Special emphasis has been placed on applications demonstrating collaboration and information sharing across institutions.

FY 2019/20 Kentucky Pediatric Cancer Research Trust Fund

Grant Program

Request for Applications (RFA)

OUR MISSION

To make childhood cancer a state health priority and give all Kentucky children access to new and innovative cancer research, development, and precision treatment — with less toxicity — while encouraging psychosocial support and focus on the complicated issues of long-term survivorship. These efforts target the needs and challenges specific to Kentucky childhood cancer epidemiology and treatments but hope to serve as a national model for how other states approach childhood cancer research.

OUR VISION

To serve as an umbrella organization to organize all pediatric cancer work across the state. It is not designed to compete with other organizations but to augment and elevate collaborative efforts; to serve as a reservoir of collaboration and information so that all efforts are amplified through an organized channel eliminating silos and fostering innovation with compassion and collaboration.

HISTORY

The KPCRTF was established in 2015 by passage of Senate Bill 82 in the Kentucky General Assembly and funded \$2.5 million each year of the biennium as part of the budget bill in 2018. The KPCRTF is an independent board administered by the Kentucky Cabinet for Health and Family Services, as described in KRS 211.596 and KRS 211.597. Eligible grant applicants include non-profit entities, educational institutions and government agencies in the Commonwealth of Kentucky. Each applicant must offer research or treatment that seeks to address the needs of the commonwealth.

The following program/service criteria to be taken into consideration:

- Eligible applicants for this RFA are limited to the University of Louisville/Norton Children's Hospital and the University of Kentucky (as described in HB 200 from the 2018 legislative session);
- Must be relevant to the mission of the Pediatric Cancer Research Trust Fund board;
- Must offer a program or service in the areas of pediatric cancer research and/or treatment;
- Must propose to address the following areas that the board has identified (research and/or treatment);

- If necessary, based on the phase and scope of the project, researchers must have institutional approval (HIPAA waiver granted/institutional review board (IRB) approval) by October 1, 2018; receipt of funds are contingent on IRB approval if IRB approval is determined to be necessary;
- Must have Cabinet for Health and Family Services IRB approval (if the scope of the project includes the need for IRB review);
- Must have conflict of interest disclosure submitted and approved by KPCRCTF board;
- Must outline how intellectual property will be shared to impact state, national and international childhood cancer mortality and morbidity;
- First preference will be to emerging, novel, and innovative high risk/high impact proposals with scientific research that can be quickly translated into new treatments for Kentucky children;
- Investigators must commit to providing testimony and information as requested by the KPCRCTF board and KY General Assembly to include legislative hearings as well as content for the KPCRCTF Annual Report;
- Investigators agree to attend, as requested and necessary, meetings of the KPCRCTF board;
- One application shall be submitted from each institution but may have multiple projects within the application. Each individual research project, when appropriate, must receive IRB approval;
- Contracts will be awarded for two fiscal years beginning July 1, 2018 through June 30, 2020;
- Modifications to the original project proposal will be considered by the board if research is failing to produce expected outcomes. Researchers will be allowed to propose a different project to the board for consideration for continued use of funds.

Summary of Use and Impact of Prior Year Funds

Kentucky Pediatric Cancer Research Trust Funds received from donations made in 2017 using the 2016 tax return check box were held for use during FY 2019 grant cycle.

Summary of Board Activities

The first meeting of the KPCRCTF board was conducted on November 28, 2016. During this meeting, members elected Jamie Bloyd as President and April Dawn Wilhoit as Vice-President of the board. Members reviewed instructions to the board set forth in the legislation. Quarterly meeting dates were set for 2017 and topics for the next meeting discussed. Subsequently, the KPCRCTF board met in January and April of 2017. These meetings were used to develop a plan of action for the coming fiscal year.

On February 15, 2017, the KPCRCTF board hosted a pediatric cancer event at the Capitol Rotunda in honor of Childhood Cancer Awareness Day. During this event the new state income tax check off was announced, the new KPCRCTF logo was revealed, and conversations were conducted with legislators. Governor Matt Bevin, State Treasurer Allison Ball, Senator Max Wise, and many other state elected officials attended the event. This event was held again on February 15, 2018 as part of International Childhood Cancer Awareness Day activities simultaneously conducted on

a global scale to increase awareness for childhood cancer as the number one cause of childhood disease-related death in the state, U.S., and internationally.

Governor Matt Bevin and First Lady Glenna Bevin hosted “PJammin at the Mansion” on October 27, 2017. Pajamas are the battle uniform for children with cancer. Too often it is a lonely battle fought isolated in hospital rooms or confined to staying at home for months – even years at a time – because of lack of immunity caused by harsh chemotherapy. Approximately 100 children living with cancer or in remission and their parents as well as possible donors were hosted at the Governor’s Mansion for a movie and a meal. \$21,000 in donations were raised during this event to help fund pediatric cancer research and treatment for Kentucky children. These donations were made to Why Not Kids, a not for profit foundation attached to the Kentucky Pediatric Cancer Research Foundation.

The KPCRTF board developed a grant program to provide funding to not-for-profit entities, academic medical centers and government agencies offering research funding and treatment for pediatric cancer to Kentucky children impacted by the disease.

Recommendations for Future Initiatives

The KPCRTF board plans to continue implementation of goals set forth in the mission statement as well as reflected in the Kentucky Cancer Action Plan with emphasis on scientific advancements in molecularly-targeted treatment and immunotherapy. The board also plans to focus on psychosocial impact of a childhood cancer diagnosis as well as long-term survivorship issues related to toxicity from treatment. Emphasis on information sharing, innovation, and collaboration across institutions will continue to guide decisions on future initiatives.

Program Financial Summary

Revenue for the KPCRTF consists of funds collected from the state income tax check off and any other proceeds from grants, contributions, appropriations, or other money made available for the purposes of the KPCRTF. Citizens may designate donations to the trust fund on their annual Kentucky state income tax form. Donations made through the trust fund check off box are sent to CHFS from the Kentucky Department of Revenue on a monthly basis.

The state income tax check off was first made available to Kentuckians in 2017 on their 2016 tax returns. The amount collected by June 30, 2017 was \$21,557. The amount collected between July 1, 2017 and June 30, 2018 was \$14,303. An additional \$5,000,000 was allocated by the legislature to the KPCRTF board for FY 2019 and FY 2020. At this time contracts to the University of Kentucky and the University of Louisville are being finalized for the projects funded. No funds have currently been expended for these projects

Appendix A

**Kentucky Revised Statutes Related to
Pediatric Cancer Research Trust Fund
and Pediatric Cancer Research Trust
Fund Board**

211.595 Pediatric cancer research trust fund.

- (1) The pediatric cancer research trust fund is hereby created as a separate trust fund. The fund shall be administered by the Cabinet for Health and Family Services.
- (2) The fund shall receive amounts collected from the income tax checkoff created in KRS 141.445, and any other proceeds from grants, contributions, appropriations, or other moneys made available for the purposes of this fund.
- (3) Notwithstanding KRS 45.229, trust fund amounts not expended at the close of a fiscal year shall not lapse but shall be carried forward to the next fiscal year.
- (4) Any interest earned on moneys in the trust fund shall become a part of the trust fund and shall not lapse.
- (5) Trust fund moneys shall be used to support pediatric cancer research and treatment for Kentucky patients. Funds shall be administered and distributed by the Pediatric Cancer Research Trust Fund Board established by KRS 211.596 for the purposes directed in this section and KRS 211.596 and 211.597.
- (6) Moneys transferred to the trust fund pursuant to KRS 141.445 are hereby appropriated for the purposes set forth in KRS 211.597.

Effective: June 24, 2015

History: Created 2015 Ky. Acts ch. 96, sec. 3, effective June 24, 2015; and ch. 108, sec. 2, effective June 24, 2015.

Legislative Research Commission Note (6/24/2015). This statute was created with identical text in 2015 Ky. Acts chs. 96 and 108, which were companion bills. These Acts have been codified together.

Legislative Research Commission Note (6/24/2015). During codification, the Reviser of Statutes has corrected the name of the Pediatric Cancer Research Trust Fund Board in this statute from the way it appeared in 2015 Ky. Acts ch. 96, sec. 3 and 2015 Ky. Acts ch. 108, sec. 2, by inserting the inadvertently omitted word "Research" in subsection (5).

211.596 Pediatric Cancer Research Trust Fund Board -- Membership -- Terms**-- Meetings.**

- (1) The Pediatric Cancer Research Trust Fund Board is hereby created for the purpose of administering and distributing funds from the trust created under KRS 211.595. The board shall be composed of nine (9) members to be appointed as follows:
 - (a) A specialist in pediatric oncology nominated by Norton Children's Hospital to be appointed by the Governor;
 - (b) A specialist in pediatric oncology nominated by the University of Kentucky Children's Hospital to be appointed by the Governor;
 - (c) A representative nominated by Kentucky Chapters of the Leukemia and Lymphoma Society to be appointed by the Governor;
 - (d) A representative nominated by Kentucky offices of the American Cancer Society to be appointed by the Governor;
 - (e) Three (3) citizens, one (1) of whom shall be a pediatric cancer survivor, or parent thereof, to be appointed by the Governor from a list of six (6) citizens nominated by Kentucky offices of the American Cancer Society;
 - (f) The secretary of the Cabinet for Health and Family Services, or the secretary's designee; and
 - (g) The commissioner of the Department for Public Health, or the commissioner's designee.

- (2) The board shall be attached to the Cabinet for Health and Family Services for administrative purposes.
- (3) The secretary of the Cabinet for Health and Family Services shall convene the first meeting of the board within sixty (60) days of June 24, 2015.
- (4) Board members shall serve without compensation, but may receive reimbursement for their actual and necessary expenses incurred in the performance of their duties.
- (5) The term of each appointed member shall be four (4) years.
- (6) A member whose term has expired may continue to serve until a successor is appointed and qualifies. A member who is appointed to an unexpired term shall serve the rest of the term and until a successor is appointed and qualifies. A member may serve two (2) consecutive four (4) year terms and shall not be reappointed for four (4) years after the completion of those terms.
- (7) A majority of the full membership of the board shall constitute a quorum.
- (8) At the first meeting, the board shall elect, by majority vote, a president who shall preside at all meetings and coordinate the functions and activities of the board. The president shall be elected or reelected each calendar year thereafter.
- (9) The board shall meet at least two (2) times annually, but may meet more frequently, as deemed necessary, subject to call by the president or by request of a majority of the board members.

Effective: June 29, 2017

History: Amended 2017 Ky. Acts ch. 80, sec. 55, effective June 29, 2017; and ch. 92, sec. 3, effective June 29, 2017. -- Created 2015 Ky. Acts ch. 96, sec. 4, effective June 24, 2015; and ch. 108, sec. 3, effective June 24, 2015.

Legislative Research Commission Note (6/29/2017). This statute was amended by 2017 Ky. Acts chs. 80 and 92, which do not appear to be in conflict and have been codified together. **Legislative Research Commission Note (6/24/2015).** This statute was created with identical text in 2015 Ky. Acts chs. 96 and 108, which were companion bills. These Acts have been codified together.

Legislative Research Commission Note (6/24/2015). During codification, the Reviser of Statutes has corrected the name of the Pediatric Cancer Research Trust Fund Board in this statute from the way it appeared in 2015 Ky. Acts ch. 96, sec. 4 and 2015 Ky. Acts ch. 108, sec. 3, by inserting the inadvertently omitted word "Research" in subsection (1).

211.597 Duties of Pediatric Cancer Research Trust Fund Board.

The Pediatric Cancer Research Trust Fund Board created by KRS 211.596 shall:

- (1) Develop a written plan for the expenditure of trust funds made available under KRS 211.595. The initial plan shall be completed on or before October 1, 2015, and shall be updated on an annual basis on or before October 1 of each year thereafter. The plan shall, at a minimum, include the following:
 - (a) A summary of existing pediatric cancer research, awareness, treatment, and funding programs provided to children of Kentucky;
 - (b) A needs assessment for the pediatric cancer patients of the Commonwealth of Kentucky that identifies additional research funding needs by cancer type and geographic area, with support for why the identified programs are needed; and
 - (c) A prioritized list of programs and research projects that the board will address with funding available through the competitive grant program established under subsection (2) of this section;

(2) (a) Promulgate administrative regulations to establish a competitive, open grant program to provide funding to not-for-profit entities, academic medical centers and government agencies offering research funding and treatment for pediatric cancer to Kentucky children impacted by the disease.

(b) The grant program shall provide funding to research projects and programs in accordance with the priorities established in the plan developed under subsection (1) of this section.

(c) The administrative regulations shall, at a minimum:

1. Establish an application process and requirements;
2. Set forth program and outcome measurement requirements;
3. Establish an application review and award process; and
4. Provide monitoring, oversight, and reporting requirements for funded programs;

(3) Promulgate administrative regulations necessary to carry out the provisions of this section and KRS 211.596; and

(4) Provide to the Governor and the Legislative Research Commission an annual report by October 1 of each year. The report shall include:

1. The plan developed under subsection (1) of this section for the expenditure of funds for the current and next fiscal year;
2. A summary of the use and impact of prior year funds;
3. A summary of the activities of the board during the prior fiscal year; and
4. Any recommendations for future initiatives or action regarding pediatric cancer research funding.

Effective: June 24, 2015

History: Created 2015 Ky. Acts ch. 96, sec. 5, effective June 24, 2015; and ch. 108, sec. 4, effective June 24, 2015.

Legislative Research Commission Note (6/24/2015). This statute was created with identical text in 2015 Ky. Acts chs. 96 and 108, which were companion bills. These Acts have been codified together.

Legislative Research Commission Note (6/24/2015). During codification, the Reviser of Statutes has corrected the name of the Pediatric Cancer Research Trust Fund Board in this statute from the way it appeared in 2015 Ky. Acts ch. 96, sec. 5 and 2015 Ky. Acts ch. 108, sec. 4, by inserting the inadvertently omitted word "Trust" in the sentence preceding subsection (1).

Legislative Research Commission Note (6/24/2015). During codification, the Reviser of Statutes has changed the way subsection (2) of this statute is subdivided from the way it appeared in 2015 Ky. Acts ch. 96, sec. 5 and 2015 Ky. Acts ch. 108, sec. 4. None of the text of that subsection was changed

Appendix B

**Childhood Cancer in Kentucky
2007 – 2016
Kentucky Cancer Registry**

Childhood Cancer in Kentucky

2007 – 2016



For more information contact:

Kentucky Cancer Registry
Markey Cancer Center
University of Kentucky
2365 Harrodsburg Road, Suite A230
Lexington, KY 40504-3381

Telephone: 859-218-6227

<http://www.kcr.uky.edu>

Suggested Citation

Kentucky Cancer Registry. 2007-2016 Childhood Cancer Incidence Report. Lexington, KY: University of Kentucky, Markey Cancer Control Program; 2018. Based on data released November 1, 2018.

Acknowledgements

The population-based childhood cancer incidence data presented in this report was made possible by the Kentucky General Assembly that passed Senate Bill 41 in April 1990. This legislation formally established the Kentucky Cancer Registry (KCR) as the official cancer surveillance program for the Commonwealth of Kentucky and mandated reporting of all cancer cases to the KCR beginning on January 1, 1991. Kentucky Revised Statute (KRS) 214.556 continues to require reporting from all health care facilities that either diagnose or treat cancer patients. Facilities include acute care hospitals, freestanding treatment centers, non-hospital (private) pathology laboratories, physician offices and genomic testing facilities. KCR gratefully acknowledges the full and active participation of facilities throughout Kentucky and a number of facilities outside of Kentucky. Their efforts are essential to complete, timely, and accurate reporting of all childhood cases occurring in Kentucky.

Beginning in 1994, the KCR was awarded funding from the Centers for Disease Control and Prevention (CDC) through the National Program of Cancer Registries (NPCR). This additional funding allows KCR to maintain a formal quality assurance program, implement complete death clearance follow back, and ensure that all cases of cancer are systematically reported by Kentucky's non-hospital facilities. In 2001, the KCR was awarded critical support from the National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) Program, to further improve patient follow-up information and support expanded quality assurance activities. Since 2011, KCR has also obtained a competitive award from the CDC for the Early Case Capture (ECC) of Pediatric and Young Adult Cancers. ECC participation permits KCR to identify and collect basic information about pediatric cancer cases much sooner following a diagnosis than is normally reported to the KCR. KCR has been successful in re-competing and sustaining all of these funding sources since the initial awards. Most recently, KCR was awarded contract renewals to continue through 2023 as an NPCR registry and through 2028 as a SEER Program registry.

Finally, special recognition is given to the professional staff of the KCR. Informatics staff develop, maintain and support software, databases and technical infrastructures used throughout Kentucky. Operations staff have developed training programs and provide ongoing support to all of the reporting facilities throughout the state. Biostatistics and epidemiology faculty provide support for cancer prevention and control activities and research with KCR data. All of these individuals are highly engaged in cancer surveillance activities and standards development at the national and international levels. KCR could not be successful without the consistent contributions of these talented and dedicated individuals.

This project has been funded in whole or in part with Federal funds from the Centers for Disease Control and Prevention and the National Cancer Institute, National Institutes of Health, Department of Health and Human Services, under Cooperative Agreement Nos. 5NU58DP005400 (ECC) and 5NU58DP006313 (NPCR), and Contract No. HHSN261201800013I (SEER).

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Introduction

This report of population-based childhood cancer incidence for the Commonwealth of Kentucky represents the most accurate data available at the time of publication. KCR collects uniform, high quality data on approximately 215 new primary cases of childhood cancer occurring in Kentucky residents each year. Childhood cancer is defined as all newly diagnosed malignant neoplasms occurring among all children living in Kentucky under the age of 20. This report provides detailed information about childhood cancer in Kentucky for the most recent ten year period of complete, population-based data collected and validated by KCR. Information includes case counts by sex, age and site groups. Site groupings by body site and histologic type are defined by the International Classification of Childhood Cancer (ICCC) (1) and permit comparisons of incidence rates within and outside of Kentucky. This report also provides information about age-adjusted childhood cancer incidence rates, defined as the number of new cases diagnosed, divided by the numbers of persons at risk in each calendar year. Age-adjustment calculates the rates according to a standard age distribution. This is necessary to allow comparisons between regions with different age distributions. All rates in this report are per 1,000,000 (million) individuals at risk for the given cancer. It should be noted that rates per million differ from reports that include adult cancers which are typically reported per 100,000. Because of the relatively small numbers of cases, rates for small geographic regions can be deemed unstable, meaning too few cases to calculate a reliable rate. Unstable rates tend to exhibit large fluctuations with the increase or decrease of even a single case from year to year and can therefore be easily misinterpreted as representing a greatly increased or diminished risk of diagnosis. As a result, unstable rates are not included in this report.

This report provides information that permits regional comparisons among Kentucky's Area Development Districts (ADD) and the Appalachian and non-Appalachian counties within the state. ADD maps display four distinct colors. Each color represents a quartile, or one-fourth of the range of incidence rates from lowest in yellow, to highest in red. Information is also provided to permit comparisons of age-adjusted rates in the United States (U.S.) with Kentucky and Appalachian Kentucky. The available U.S. data are not as current as KCR data, therefore the national comparisons utilize data from an earlier period of time.

Overview

Childhood cancer is relatively rare, with less than 1% of all cancers diagnosed in Kentucky occurring among children under the age of 20. Over 83% of children diagnosed with cancer survive at least 5 years (3). However, cancer is the second leading cause of death in children. Brain and central nervous system (CNS) tumors have recently replaced leukemia as the leading cause of cancer death among children (4). A cancer diagnosis is severely burdensome for these children and their families. In addition to the side effects from surgeries, chemotherapeutics and/or radiation on developing body systems, there are often lifelong economic and social costs for affected families.

From 2007 through 2016, the most recent ten years of complete data presented in this report, 2,152 children in Kentucky were diagnosed. Cancer occurred more frequently among males (54%) than females (46%). The frequency of cancer diagnoses varied by age, with cancers occurring most frequently among

children ages 0-4, followed by children ages 15-19, 10-14 and 5-9, respectively. Males were diagnosed with more cancers across all site groups except for epithelial tumors and melanoma and renal tumors. Among all Kentucky children, leukemia occurred most frequently, followed by brain and CNS tumors, lymphoma, epithelial tumors and melanoma and the other remaining site groups.

The frequency of diagnoses by cancer site group also varied by age group. Of note, a greater proportion of leukemia cases occurred among children ages 0-4 and 5-9. A greater proportion of children ages 5-9 also experienced the greatest proportion of brain and CNS tumors. Lymphoma, epithelial tumors and melanoma, and germ cell and gonadal tumors increased proportionally with age, while sympathetic nervous system tumors, renal tumors, retinoblastoma, and hepatic tumors decreased proportionally with age. The greatest proportion of soft tissue sarcomas occurred among children ages 10-14. The age-adjusted incidence rates of childhood cancer have increased by over 1.8% annually among both males and females over this ten-year time period. While of concern, this trend is consistent with observations in the U.S. as a whole (3).

Regional comparisons within Kentucky indicate that the highest rates tend to occur in the eastern regions of the state with Appalachian Kentucky experiencing a higher rate than non-Appalachian Kentucky. However, we do not observe statistically significant differences. According to the most recent national data available (2006-2015), Kentucky's age-adjusted childhood cancer incidence rate for all cancer sites is approximately the same as in the U.S. (2). However, rates in Appalachian Kentucky are higher than in the U.S. for both males and females. Comparisons to U.S. rates by site group indicate that Appalachian children in Kentucky have higher rates across all major site groups except for soft tissue sarcomas, bone tumors, and renal tumors. Of particular concern, rates of brain and CNS tumors are significantly higher in Kentucky compared to the U.S. and even higher among Appalachian children in Kentucky. Compared to other states, Kentucky was ranked 22nd for all invasive cancer sites combined. However, Kentucky had the 5th highest rate for both retinoblastoma and hepatic tumors and the 6th highest rate for brain and CNS tumors.

Children's Oncology Group (COG) affiliated facilities are likely to be in a position to offer the most current recommended treatment regimens for Kentucky children as well as opportunities to participate in life saving clinical trials. However, KCR data indicate that 18.7% of Kentucky children were treated outside of COG facilities in Kentucky during this reporting period.

1. Steliarova-Foucher E, Stiller C, Lacour B and Kaatsch P. International Classification of Childhood Cancer, third edition. Cancer 103:1457-67, 2005.

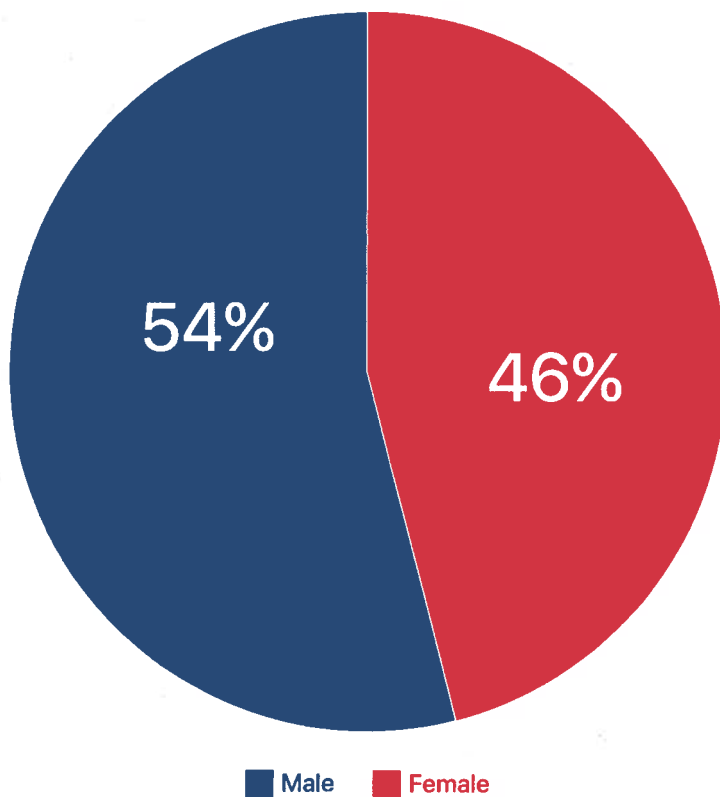
2. United States Cancer Statistics: 1999 - 2015 Incidence, WONDER Online Database. United States Department of Health and Human Services, Centers for Disease Control and Prevention and National Cancer Institute; 2018. Accessed at <http://wonder.cdc.gov/cancer-v2015.html>.

3. Noone AM, Howlader N, Krapcho M, Miller D, Brest A, Yu M, Ruhl J, Tatalovich Z, Mariotto A, Lewis DR, Chen HS, Feuer EJ, Cronin KA (eds). SEER Cancer Statistics Review, 1975-2015, National Cancer Institute. Bethesda, MD, https://seer.cancer.gov/csr/1975_2015/, based on November 2017 SEER data submission, posted to the SEER web site, April 2018.

4. Curtin SC, Minino AM, Anderson RN. Declines in cancer death rates among children and adolescents in the United States, 1999-2014. National Center for Health Statistics Data Brief 2016; (257):1-8.

CHILDHOOD CANCER INCIDENCE IN KENTUCKY ALL SITES, 2007-2016

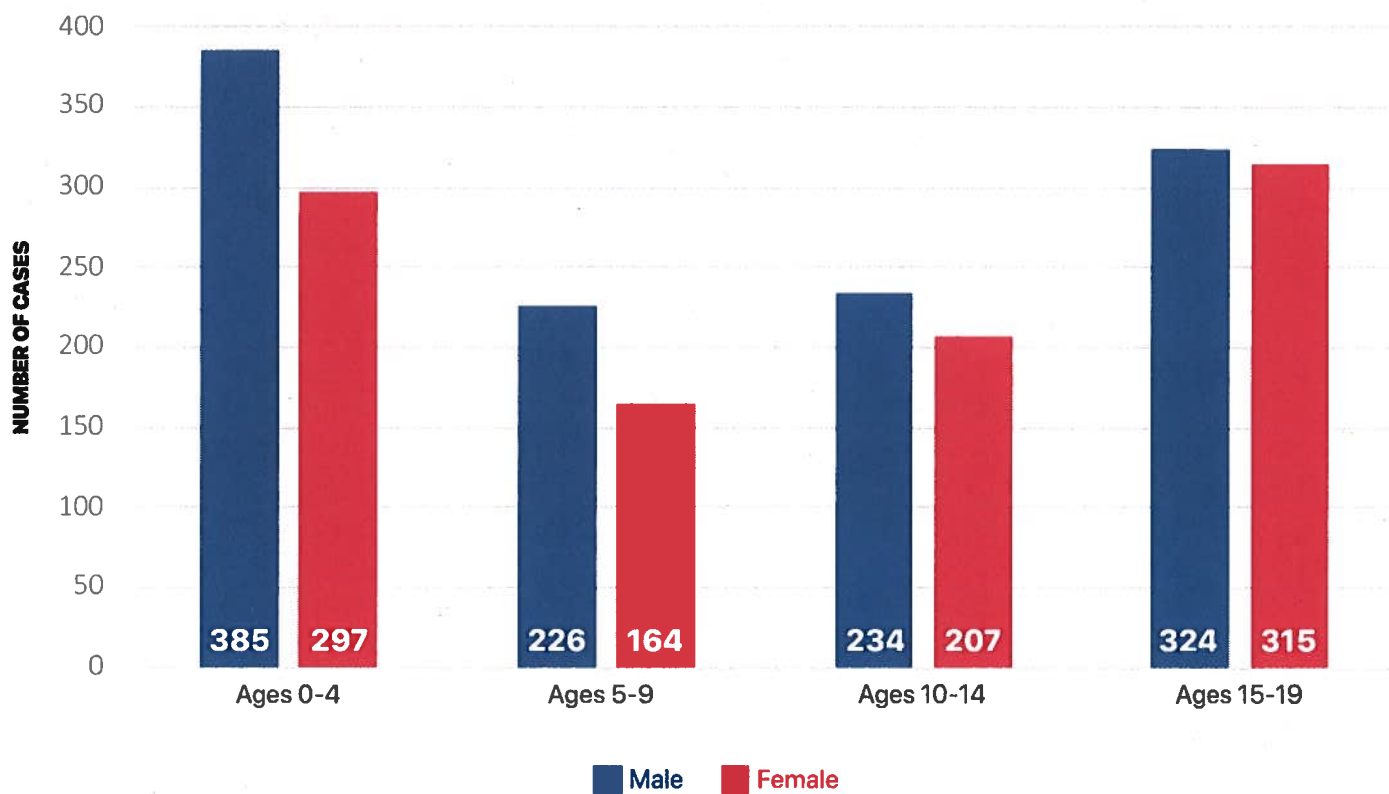
PROPORTION OF CASES BY SEX



Sex	Number of Cases (Percent)
Male	1,169 (54%)
Female	983 (46%)
Total	2,152

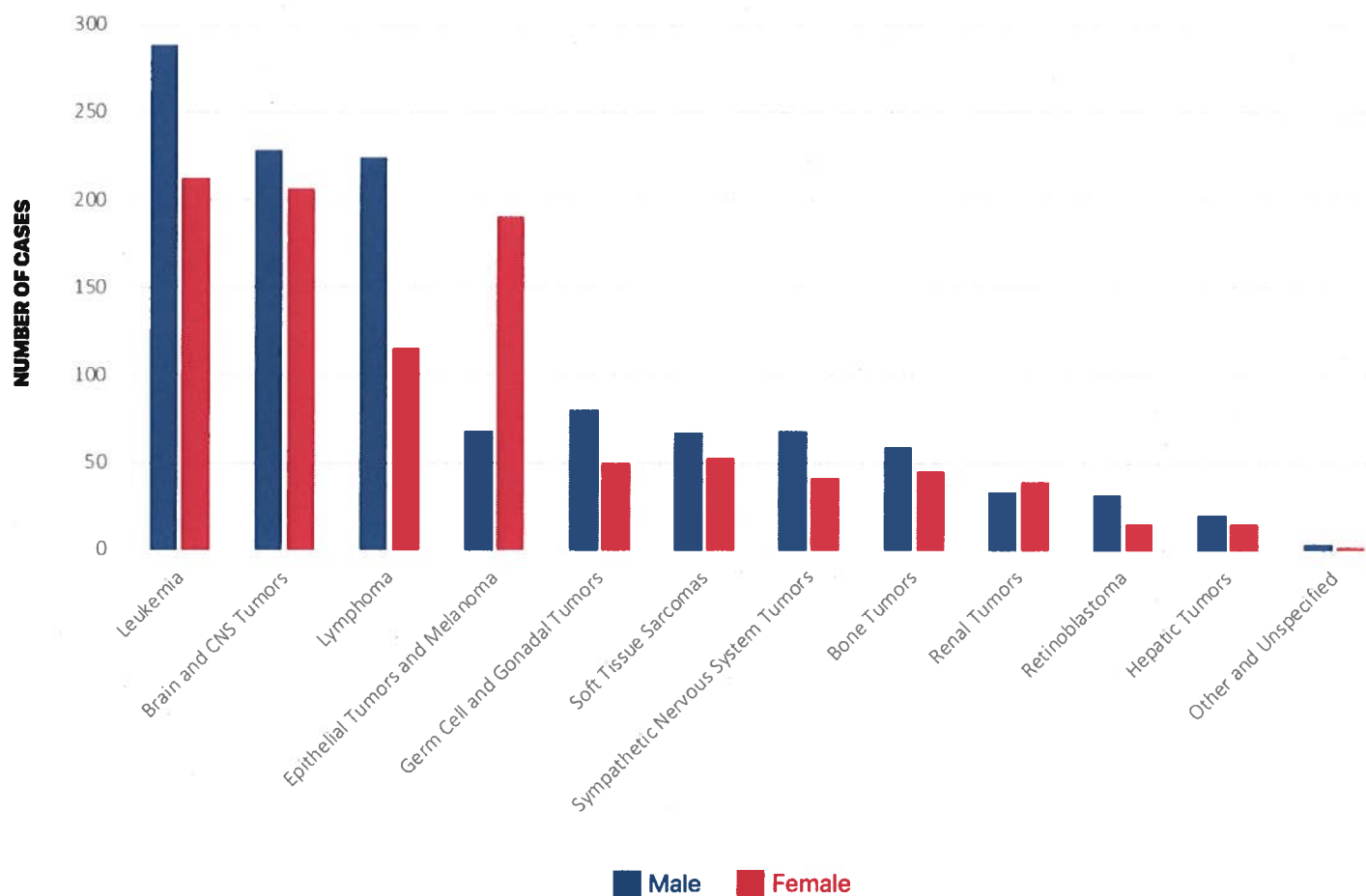
CHILDHOOD CANCER INCIDENCE IN KENTUCKY ALL SITES, 2007-2016

CASES BY SEX AND AGE AT DIAGNOSIS



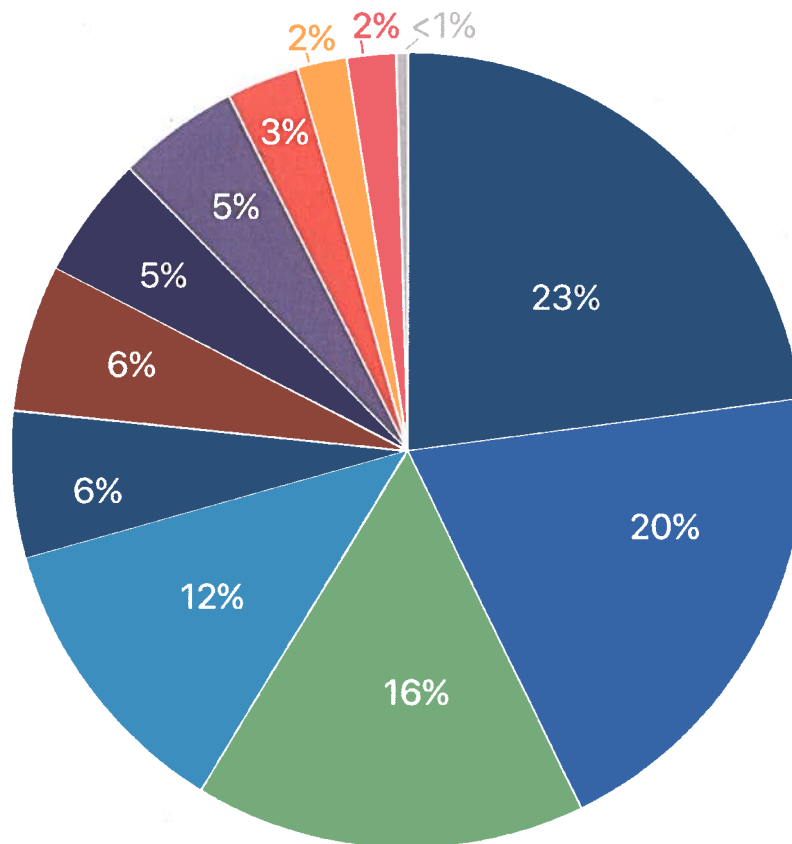
CHILDHOOD CANCER INCIDENCE IN KENTUCKY BY SITE GROUP, 2007-2016

CASES BY SITE GROUP AND SEX



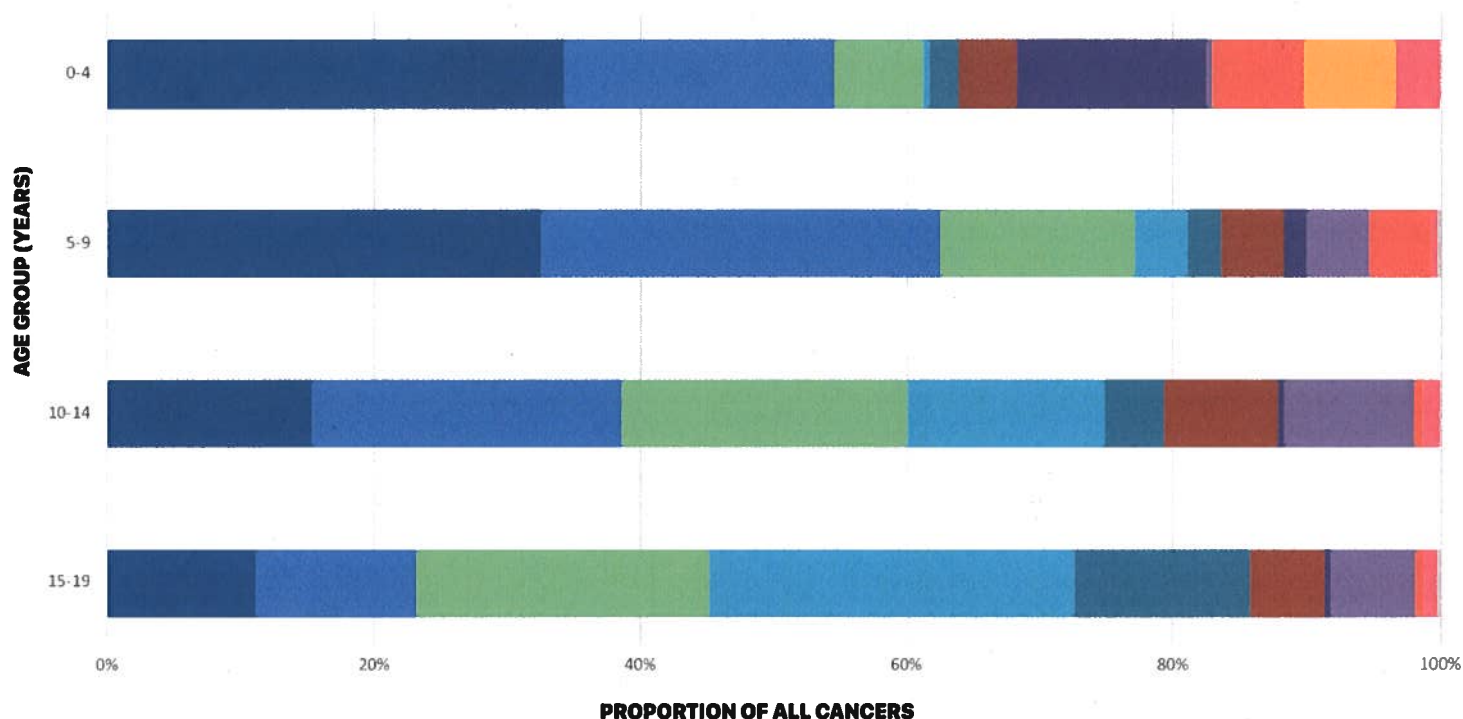
CHILDHOOD CANCER INCIDENCE IN KENTUCKY BY SITE GROUP, 2007-2016

PROPORTION OF CASES BY SITE GROUP



CHILDHOOD CANCER INCIDENCE IN KENTUCKY BY SITE GROUP, 2007-2016

PROPORTION OF CASES BY SITE GROUP AND AGE GROUP



CHILDHOOD CANCER INCIDENCE RATES IN KENTUCKY BY SITE GROUP, 2007-2016

MALE AND FEMALE

Site Group	Male Cases	Male Age-Adjusted Rate	Female Cases	Female Age-Adjusted Rate
All Sites	1,169	200.2	983	176.9
Leukemia	288	49.4	212	38.1
Brain and CNS Tumors	228	39.2	206	37.2
Lymphoma	224	38.5	115	20.7
Epithelial Tumors and Melanoma	68	11.6	190	34.1
Germ Cell and Gonadal Tumors	80	13.5	49	8.8
Soft Tissue Sarcomas	67	11.5	53	9.6
Sympathetic Nervous System Tumors	68	11.5	41	7.3
Bone Tumors	59	10.2	45	8.2
Renal Tumors	33	5.7	39	7.0
Retinoblastoma	32	5.4	15	2.7
Hepatic Tumors	20	3.4	15	2.7
Other and Unspecified	2	0.3	1	0.2

Note: All rates are per 1,000,000. Rates are age-adjusted to the 2000 U.S. Standard Million Population.

CHILDHOOD CANCER INCIDENCE RATES IN KENTUCKY ALL SITES, 2007-2016

BOTH SEXES

Year	2007	2008	2009	2010	2011	2012	2013	2014	2015	2016	2007-2016
Population at Risk	1,133,012	1,142,982	1,144,346	1,146,057	1,140,477	1,133,846	1,131,606	1,127,736	1,125,457	1,124,893	11,350,412
Total Cases	206	188	209	211	229	217	211	214	231	236	2,152
Crude Rate	181.8	164.5	182.6	184.1	200.8	191.4	186.5	189.8	205.2	209.8	189.6
Age-Adjusted Rate	180.2	163.6	181.7	183.0	200.1	190.9	186.2	189.3	204.5	209.0	188.8
95% CI Lower	156.4	141.1	157.9	159.2	175.0	166.3	161.9	164.8	179.0	183.2	180.9
95% CI Upper	206.5	188.8	208.1	209.5	227.8	218.1	213.0	216.4	232.7	237.4	197.0

Note: All rates are per 1,000,000. Rates are age-adjusted to the 2000 U.S. Standard Million Population.

AGE-ADJUSTED INCIDENCE RATE TREND



Incidence rates have increased approximately 1.8% annually over this ten year time period. The trend line shown in the figure is based on a linear regression. The 1.8% annual percent change (APC) is calculated using the JointPoint Trend Analysis software package developed by NCI SEER (<https://surveillance.cancer.gov/joinpoint/>)

CHILDHOOD CANCER INCIDENCE RATES IN KENTUCKY ALL SITES, 2007-2016

MALE

Year	2007	2008	2009	2010	2011	2012	2013	2014	2015	2016	2007-2016
Population at Risk	580,973	585,519	586,178	587,012	584,561	581,193	580,303	578,156	576,795	576,056	5,816,746
Total Cases	117	95	94	127	129	124	122	110	130	121	1,169
Crude Rate	201.4	162.2	160.4	216.3	220.7	213.3	210.2	190.3	225.4	210.1	201.0
Age-Adjusted Rate	200.1	160.7	159.9	214.4	220.3	212.8	209.8	189.9	224.5	209.3	200.2
95% CI Lower	165.5	130.0	129.2	178.8	183.9	177.0	174.2	156.1	187.6	173.7	188.9
95% CI Upper	239.8	196.5	195.6	255.2	261.7	253.7	250.5	228.8	266.6	250.2	212.0

Note: All rates are per 1,000,000. Rates are age-adjusted to the 2000 U.S. Standard Million Population.

CHILDHOOD CANCER INCIDENCE RATES IN KENTUCKY ALL SITES, 2007-2016

FEMALE

Year	2007	2008	2009	2010	2011	2012	2013	2014	2015	2016	2007-2016
Population at Risk	552,039	557,463	558,168	559,045	555,916	552,653	551,303	549,580	548,662	548,837	5,533,666
Total Cases	89	93	115	84	100	93	89	104	101	115	983
Crude Rate	161.2	166.8	206.0	150.3	179.9	168.3	161.4	189.2	184.1	209.5	177.6
Age-Adjusted Rate	159.3	166.7	204.7	150.1	178.9	168.0	161.2	188.8	183.5	208.6	176.9
95% CI Lower	127.9	134.6	168.9	119.7	145.6	135.6	129.5	154.3	149.4	172.2	166.0
95% CI Upper	196.1	204.3	245.7	185.8	217.6	205.8	198.4	228.8	222.9	250.4	188.3

Note: All rates are per 1,000,000. Rates are age-adjusted to the 2000 U.S. Standard Million Population.

CHILDHOOD CANCER INCIDENCE RATES IN KENTUCKY ALL SITES, 2007-2016

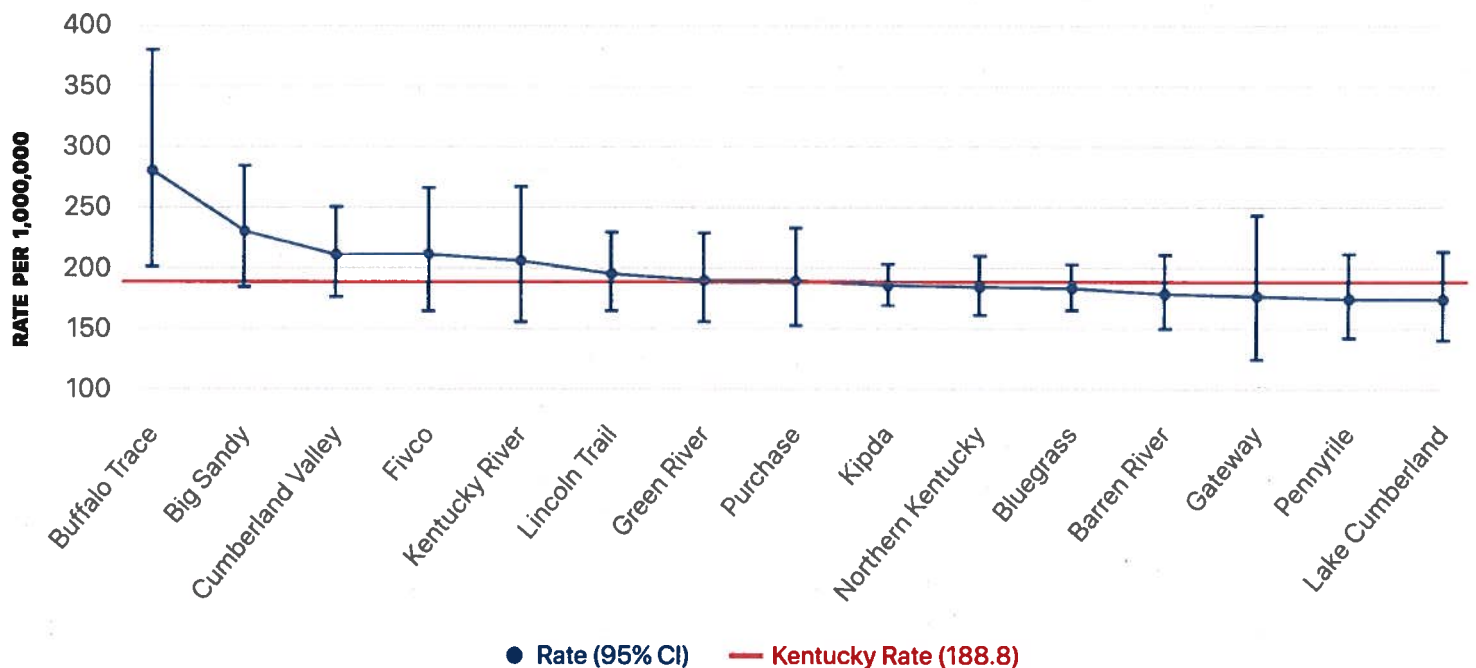
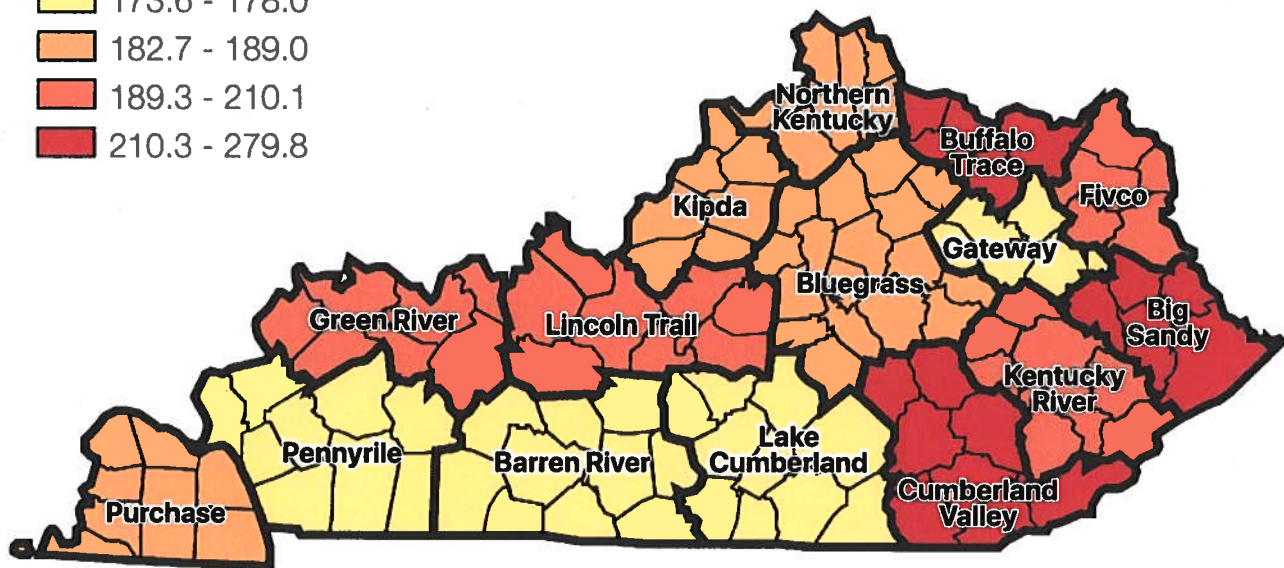
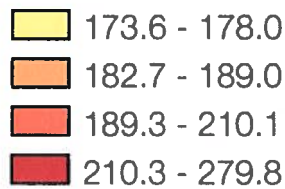
BY AREA DEVELOPMENT DISTRICT

Area Development District	Population at Risk	Cases	Crude Rate	Age-Adjusted Rate	95% CI Lower	95% CI Upper
Buffalo Trace	147,612	41	277.8	279.8	200.8	379.5
Big Sandy	371,792	86	231.3	229.8	183.8	283.8
Cumberland Valley	610,026	129	211.5	210.3	175.6	249.9
Fivco	332,436	70	210.6	210.1	163.8	265.5
Kentucky River	273,198	56	205.0	205.3	155.0	266.5
Lincoln Trail	740,191	144	194.5	194.6	164.1	229.1
Green River	568,326	108	190.0	189.3	155.2	228.5
Purchase	477,088	90	188.6	189.0	152.0	232.4
Kipda	2,507,074	465	185.5	185.1	168.6	202.7
Northern Kentucky	1,225,412	225	183.6	183.7	160.5	209.4
Bluegrass	2,013,886	371	184.2	182.7	164.5	202.3
Barren River	767,123	137	178.6	178.0	149.4	210.4
Gateway	212,768	37	173.9	176.1	123.8	242.9
Pennyrile	582,571	102	175.1	173.9	141.7	211.2
Lake Cumberland	520,909	91	174.7	173.6	139.8	213.2
State	11,350,412	2,152	189.6	188.8	180.9	197.0

Note: All rates are per 1,000,000. Rates are age-adjusted to the 2000 U.S. Standard Million Population.

CHILDHOOD CANCER INCIDENCE RATES IN KENTUCKY ALL SITES, 2007-2016

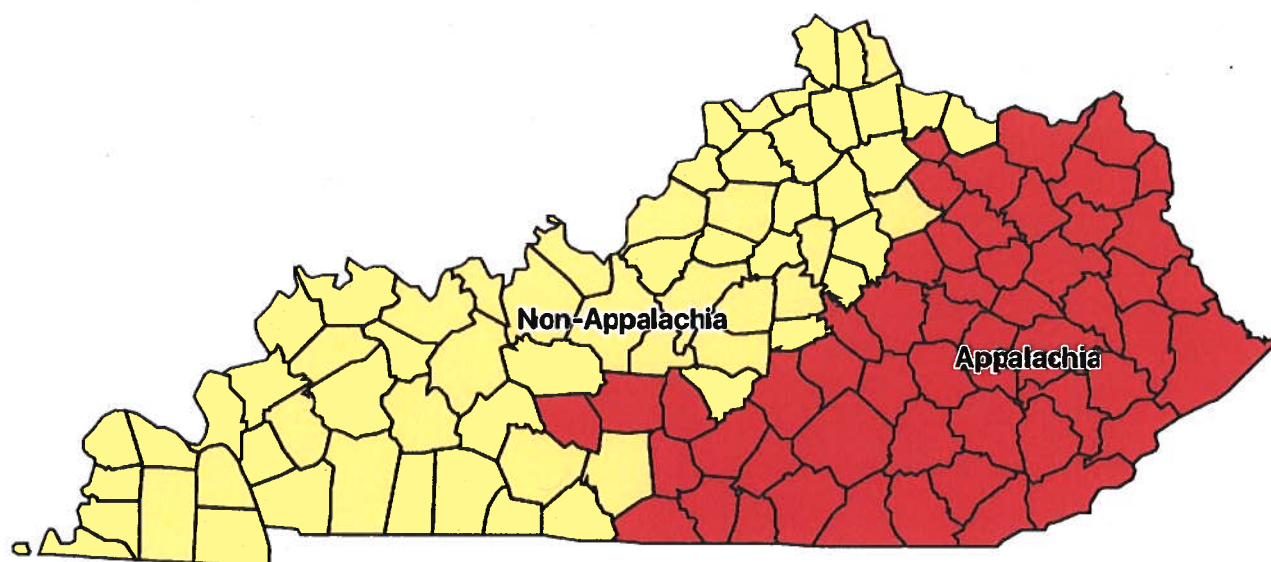
AGE-ADJUSTED RATES BY AREA DEVELOPMENT DISTRICT



Note: All rates are per 1,000,000. Rates are age-adjusted to the 2000 U.S. Standard Million Population.

CHILDHOOD CANCER INCIDENCE IN KENTUCKY ALL SITES, 2007-2016

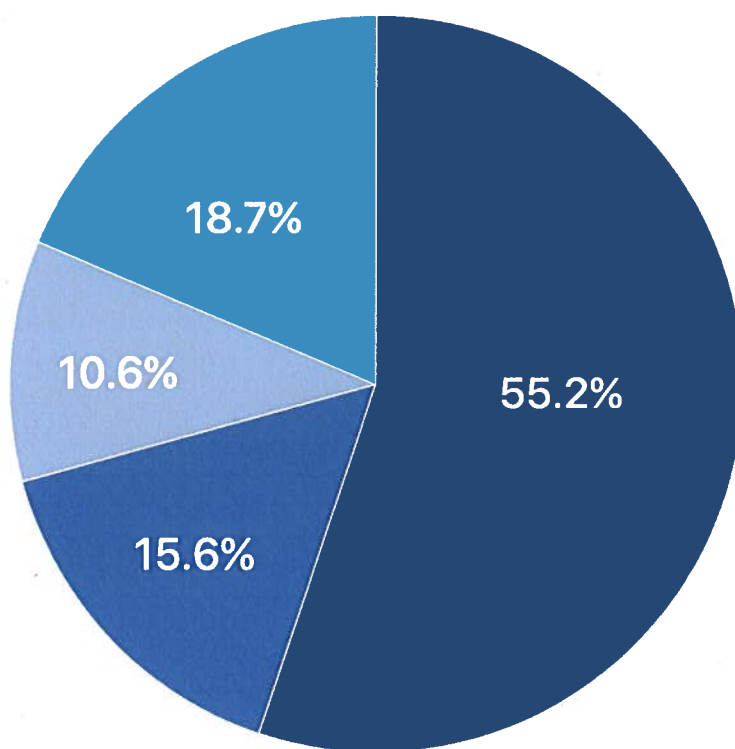
AGE-ADJUSTED RATES BY APPALACHIAN REGION



Region	Population at Risk	Cases	Crude Rate	Age-Adjusted Rate	95% CI Lower	95% CI Upper
Appalachia	2,977,907	612	205.5	204.3	188.4	221.1
Non-Appalachia	8,372,505	1540	183.2	183.2	174.2	192.6
State	11,350,412	2,152	189.6	188.8	180.9	197.0

Note: All rates are per 1,000,000. Rates are age-adjusted to the 2000 U.S. Standard Million Population.

KENTUCKY CASES SEEN IN CHILDREN'S ONCOLOGY GROUP (COG) FACILITIES, 2007-2016



■ Kentucky COG Facilities
 ■ Ohio COG Facilities
 ■ Tennessee COG Facilities
 ■ Non-COG Facilities

Facility Type	Number of Cases (Percent)
Kentucky COG Facilities	1,187 (55.2%)
Ohio COG Facilities	335 (15.6%)
Tennessee COG Facilities	228 (10.6%)
Non-COG Facilities	402 (18.7%)
Total	2,152

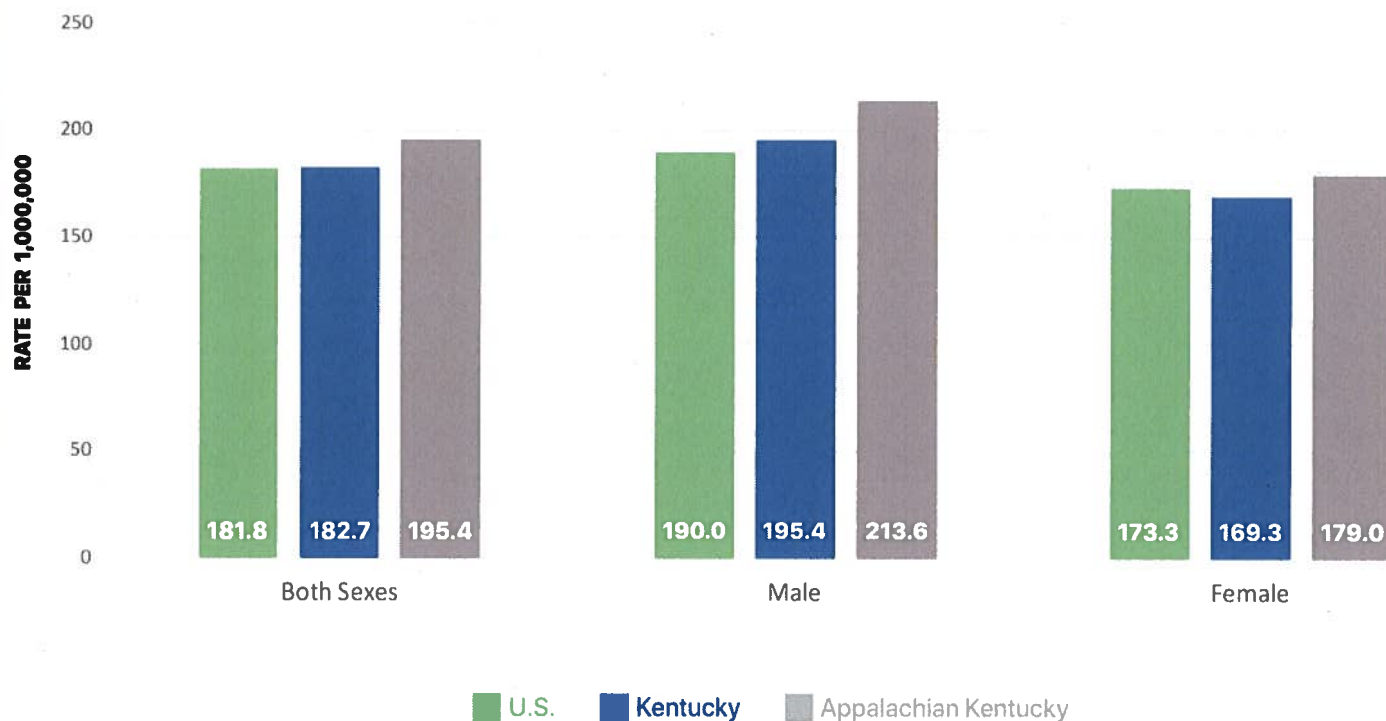
Childhood Cancer Incidence Rates in Kentucky Compared to U.S.

2006 - 2015



AGE-ADJUSTED CHILDHOOD CANCER INCIDENCE RATES ALL SITES, 2006-2015

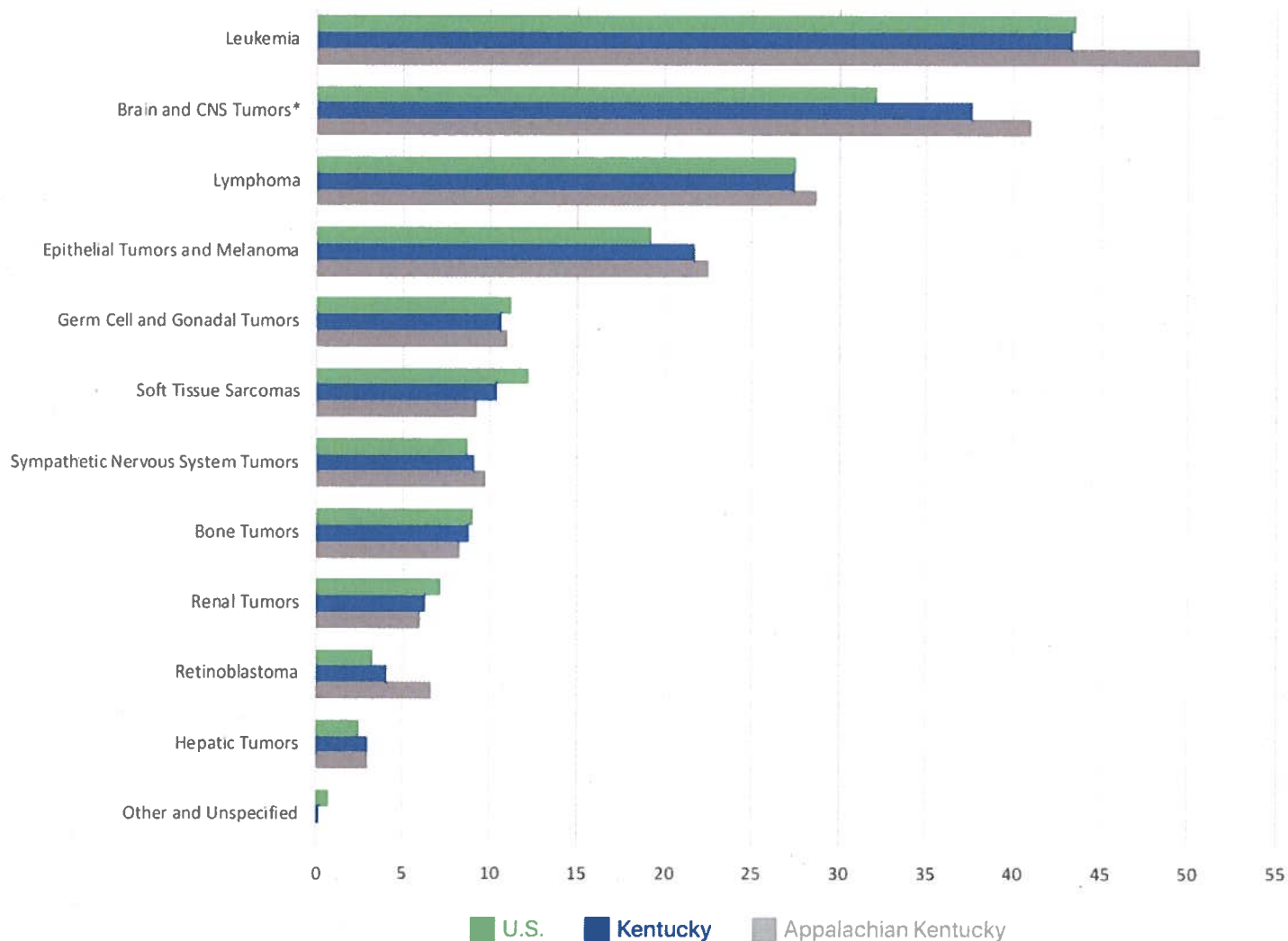
KENTUCKY COMPARED TO U.S.



Note: All rates are per 1,000,000. Rates are age-adjusted to the 2000 U.S. Standard Million Population.

AGE-ADJUSTED CHILDHOOD CANCER INCIDENCE RATES BY SITE GROUP, 2006-2015

KENTUCKY COMPARED TO U.S.



***P < 0.05 (Kentucky compared to U.S. Rate and Appalachian Kentucky compared to U.S. Rate)**

Note: All rates are per 1,000,000. Rates are age-adjusted to the 2000 U.S. Standard Million Population.

AGE-ADJUSTED CHILDHOOD CANCER INCIDENCE RATES BY SITE GROUP, 2006-2015

KENTUCKY RANKINGS COMPARED TO U.S. STATES

Site Group	Ranking
All Sites	22nd
Leukemia	36th
Brain and CNS Tumors	6th
Lymphoma	27th
Epithelial Tumors and Melanoma	13th
Germ Cell and Gonadal Tumors	23rd
Soft Tissue Sarcomas	47th
Sympathetic Nervous System Tumors	16th
Bone Tumors	24th
Renal Tumors	40th
Retinoblastoma	5th
Hepatic Tumors	5th
Other and Unspecified	30th

Definitions

Age-Adjusted Rate	A statistical adjustment applied to crude rates to permit comparisons of populations with different age structures. The 2000 Standard U.S. Million Population is commonly used in age-adjusted rates for cancer research in U.S.
Annual Percent Change (APC)	Change in annual rates over time. The APC in this report was calculated through a log-transformation of the age-adjusted rates using the JoinPoint Trend Analysis software. https://surveillance.cancer.gov/joinpoint/
Appalachian Region	Groups of counties designated by the Appalachian Regional Commission's authorizing legislation. The region follows the spine of the Appalachian Mountains from southern New York to northern Mississippi. The current Kentucky Appalachian region includes 54 Kentucky counties https://www.arc.gov/appalachian_region/TheAppalachianRegion.asp
Area Development Districts	Groups of contiguous counties in Kentucky, comprising 15 area development districts. https://www.kyatlas.com/kentucky-adds.html
Cases	Total number of new incident cancer cases diagnosed in a given year or time period.
Childhood Cancer	A malignant cancer diagnosed in an individual under the age of 20.
Children's Oncology Group (COG)	A large group of researchers, hospitals, and cancer centers that get support from the National Cancer Institute (NCI) to study childhood cancer. https://www.childrensoncologygroup.org/index.php/aboutus
Crude Rate	An unadjusted incidence rate, calculated as the number of newly diagnosed cases divided by the population at risk.
Diagnosis Year	Year in which a cancer is first diagnosed.
Incidence Rate	Rate of new cancer diagnoses in a given year or time period.
P < 0.05	The P value, or calculated probability under the null hypothesis is used to quantify the idea of statistical significance of evidence. P < 0.05 is a convention generally accepted as representing a statistically significant finding.
Population at Risk	Number of individuals living in a geographical region and at risk of being diagnosed with cancer for a given year or time period.
Site Group	Type of cancer, grouped by topography and histology, as defined by the International Classification of Childhood Cancer. (1)
US Standard Million Population	The age distribution of individuals living in the U.S. in a given year, per million residents, as defined by the U.S. Census.
95% Confidence Interval (CI)	Specifies the precision of the age-adjusted rate measurement, resulting in a 95% certainty that the confidence interval includes the true value of the measurement.

1. Steliarova-Foucher E, Stiller C, Lacour B and Kaatsch P. International Classification of Childhood Cancer, third edition. Cancer 103:1457-67, 2005.

Staff of the Kentucky Cancer Registry

Director	Eric B. Durbin, DrPH, MS
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Staff Biostatistician	Quan Chen, DrPH



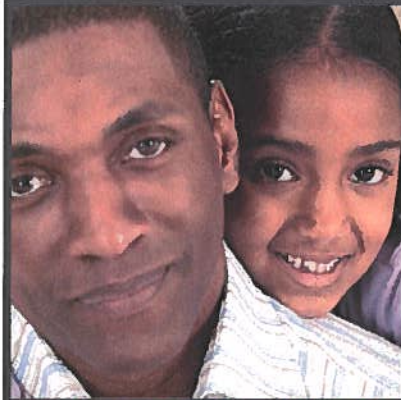
Appendix C

Kentucky Cancer Consortium Cancer Action Plan Childhood Cancer Section



A partnership for life.

www.KyCancerC.org



Kentucky Cancer Consortium

CANCER ACTION PLAN

a blueprint for cancer prevention
and control in our state



Goal 10: Quality of Life

Promote overall health of Kentucky cancer survivors from diagnosis onward, to increase quality of life.

Childhood Cancer Survivors

Focus Areas

- Public Health Needs of Adult Cancer Survivors
- **Childhood Cancer Survivors**
- Hospice and Palliative Care

Objectives

Measure	Baseline	Target
% of KY pediatric oncology patients seen at Children's Oncology Group facilities	81% ¹	90% by 2021
Number of KY pediatric oncology patients evaluated at Long-Term Follow Up Clinics.	XX ²	XX by 2021
Five year survival rate of KY childhood cancer patients.	84% ³	87% by 2021
Number of KY-specific resource guides available to pediatric cancer patients and their families/careivers.	O ⁴	1 by 2021
Number of instructional hours offered under KY's home/hospital instruction programs.	Minimum of two (2) one (1) hour visits per week. ⁵	Minimum of five (5) hours per week by 2021.
Number of statewide networking & professional development meetings of childhood cancer advocates & professionals.	O ⁶	One meeting annually (five total) by 2021.

Policy, Systems, and Environmental Changes

- Work with childhood cancer advocacy organizations to support efforts aimed at improving Kentucky pediatric cancer patients' quality of life from diagnosis onward.
- Educate patients, parents and educators on academic challenges faced by childhood cancer patients, and educate legislators as to the importance of comprehensive home/hospital instruction administrative regulations in Kentucky.
- Expand workforce training in pediatric palliative care.
- Promote increased access to integrated palliative care services for children facing any stage of cancer.
- Work with public health economists to calculate the financial impact of childhood cancer in Kentucky (loss of income by parents; out of pocket costs for care; data on financial hardships/medical bankruptcy; long-term financial impact on pediatric cancer survivors such as employability and insurability).

Health Equity

- Increase research to better understand and address differences in childhood cancer occurrence and survival between Appalachian and Non-Appalachian regions.

Communication/Education

- Increase education about long-term consequences of cancer treatment for pediatric, adolescent/young adult, and adult cancer patients.
- Educate patients and their families about the need for long term follow-up care to monitor for late effects of childhood cancer treatment and promote healthy survivorship.
- Encourage families of children with cancer to utilize treatment summaries and survivorship care plans.
- Conduct website research to identify available childhood cancer educational resources.
- Work with Kentucky Children's Alliance, Kentucky COG facilities staff, and other interested partners and advocates to create a list of childhood cancer resources utilized by pediatric cancer patients and their families.
- Support and promote awareness for programs that provide psychosocial, physical, logistical, and emotional support for patients and their families.
- Identify and address need for consumer friendly explanations of pediatric clinical trials, informed consent, and referral patterns.
- Identify and address family educational needs (diagnosis, treatment, late-effects, psychosocial support programs, sibling support, respite care).
- Work with school intervention specialists to raise awareness among Kentucky patients, families, educators and administrators as to support that should be available through the school system (IEP, educational consultants, etc.).

¹Kentucky Cancer Registry, 2009-2013, accessed September 2016. ²Data pending from Sherry Bayliff, University of Kentucky's Long-Term Follow-Up Clinic, based on those seen from 2011-2016.

³National Cancer Institute, SEER Stat database, 2009-2013. ⁴Meeting of Kentucky Cancer Consortium childhood Cancer member organizations, August 2016. ⁵704 KAR 7:120. ⁶Kentucky Cancer Consortium program records, 2001-2016.

Goal 10: Quality of Life

Promote overall health of Kentucky cancer survivors from diagnosis onward to increase quality of life.

Childhood Cancer Survivors

Focus Areas

- Public Health Needs of Adult Cancer Survivors
- Childhood Cancer Survivors
- Hospice and Palliative Care

“In the U.S. in 2016, an estimated 10,380 new cases of cancer will be diagnosed among children from birth to 14 years, and about 1,250 children are expected to die from the disease.¹

In Kentucky, approximately 238 children were diagnosed with invasive childhood cancer in 2015.²

Communication/Education (cont.)

- Increase general awareness of incidence and impact of pediatric cancer on America's children.
- Increase awareness of clinical trials in the pediatric/adolescent population.
- Increase awareness of need for novel pediatric cancer therapies
- Increase awareness of the impact of pediatric cancer on survivors and their families.

Healthcare Professionals

- Promote utilization of recommendations/standards for follow-up care (e.g., COG Passport for Care; Psychosocial Standards of Care Project for Childhood Cancer (PSCPCC)), including baselines for neuro-cognitive status and follow-up screening.
- Increase continuing education opportunities for pediatricians and primary care providers regarding diagnosis of childhood cancer and importance of referrals to COG facilities.
- Adopt a standardized neuro-cognitive baseline and follow up assessments as established by COG.
- Increase collaborations among Kentucky partner organizations to develop childhood cancer awareness continuing education modules for tele-health and online use.

Insurers

- Work to increase access and coverage of treatment at COG facilities for all childhood cancer patients.
- Educate decision makers on the need for adequate reimbursement for pediatric home, hospice and palliative care.
- Advocate for coverage of appropriate psychosocial services for parents and siblings of children with cancer.

Worksite Wellness

- Educate human resource professionals as to the full extent of resources available to pediatric cancer caregivers through the Family Medical Leave Act.

Data & Research

- Support research leading to new therapies targeted specifically for children with cancer that are effective and less toxic.
- Promote basic/molecular research leading to understanding the causes of pediatric cancers.
- Increase access to all phases of pediatric oncology clinical trials.
- Promote research to improve the quality of life for survivors that address the physical, cognitive and psychosocial consequences of treatment from diagnosis through late effects.
- Work with state and national partners to support funding for pediatric cancer research.
- Support development of funding mechanisms to support non-profits providing quality educational materials to children with cancer and their families.

Although pediatric cancer death rates have declined by nearly 70% over the past four decades, cancer remains the leading cause of death from disease among children.¹

Age-Adjusted Childhood Cancer Incidence Rates in Kentucky
All Sites, 1999 - 2013
By Area Development District
Age Adjusted to the 2000 U.S. Standard Million Population
Kentucky Rate: 176.0 / per 1,000,000



All rates per 1,000,000.
Data accessed August 29, 2016. Based on data released Jan 2016.
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- | | |
|---------------------|----------------------|
| 1 Northern Kentucky | 9 Lincoln Trail |
| 2 Buffalo Trace | 10 Purchase |
| 3 Flaco | 11 Pennyrite |
| 4 Kipde | 12 Barren River |
| 5 Bluegrass | 13 Lake Cumberland |
| 6 Gateway | 14 Cumberland Valley |
| 7 Big Sandy | 15 Kentucky River |
| 8 Green River | |

¹National Cancer Institute. ²Kentucky Cancer Registry

Goal 10: Quality of Life

Promote overall health of Kentucky cancer survivors from diagnosis onward, to increase quality of life.

Hospice and Palliative Care

Focus Areas

- Public Health Needs of Adult Cancer Survivors
- Childhood Cancer Survivors
- Hospice and Palliative Care

Objectives

Measure	Baseline	Target
The number of providers certified in Hospice and Palliative Medicine in Kentucky	332 ¹	350 by 2020
Kentucky's grade regarding the quality of its policies affecting pain treatment	B+ ²	A by 2020
By 2020, for cancer patients with a terminal diagnosis, increase median length of stay in hospice care. ⁴ <i>*This will serve as a proxy measure for Kentucky as there is no statewide data source available.</i>		

Policy, Systems, and Environmental Changes

- Encourage oncology and inpatient programs to incorporate components of palliative care.
- Educate key decision makers regarding policy changes that will support reimbursement for advanced care planning conversations and concurrent use of hospice care during active treatment.
- Educate clinic staff to facilitate culturally competent conversations about advance care planning.
- Monitor changes in State and Federal legislation and funding regarding palliative care, and serve as a source of this information for health care providers, institutions, voluntary organizations and others.
- Promote completion of advanced care planning documents for all cancer patients near the time of diagnosis or early in treatment.
- Support implementation of palliative care programs for children.

Communication/Education

- Encourage health care providers, institutions, voluntary organizations, government agencies and others to provide education and information on palliative care and hospice care, including scope of services, locations, access to care and reimbursement.
- Work with member organizations to do targeted outreach and education about the benefits of hospice.
- Document and promote the availability of palliative care in inpatient and outpatient settings in NCI-designated cancer centers, tertiary hospitals, children's hospitals and community cancer centers in Kentucky.

Healthcare Professionals

- Work with associations representing health care professionals to promote hospice and palliative care certification and credentialing.
- Promote training for health professionals in both adult and pediatric hospice and palliative care.

Insurers

- Educate public and private insurers regarding policy changes that will support reimbursement for advanced care planning conversations and concurrent use of hospice care during active treatment.

¹Baseline: 94 MDs, American Board of Medical Specialties, 2014. 9 APRNs & 229 RNs, Nat'l Board for Certification of Hospice and Palliative Nurses, 2014. ² State Pain Policy Advocacy Network, 2013. ³ 20 days, Hospice of the Bluegrass, 2014